

356 Las Olas Drive
Melbourne Beach, FL 32951
(321) 724-8899



Parents Planning Programs (PPP)
for the Developmentally Disabled
of Florida, Inc.
a 501c(3) non profit corporation

fax (321) 321-5851
pppflorida@cfl.rr.com
<http://www.pppflorida.org>

Sent electronically: OIRA_SUBMISSION@OMB.EOP.GOV
By Fax: 202 395-7285

May 29, 2012

To: Office of Management & Budget

Attn: Desk Officer for the Administration for Children & Families

Re: State Council on Developmental Disabilities Annual Program Performance Report
OMB No.: 0980-0172

Description: A Developmental Disabilities Council Annual Program

To Whom It May Concern:

I am writing in response to the request by your agency to comment on the requirement by federal statute that State Councils on Developmental Disabilities (“DD Councils”) submit annual reports for the preceding fiscal year detailing council activities and accomplishments. More specifically, I would like to share my knowledge of recent events which have a bearing on the philosophy and activities of the Florida Council on Developmental Disabilities (FDDC) who influence the rulemaking activities of Center for Medicare and Medicaid Services for people with developmental disabilities. Thank you for the opportunity to comment.

I am the mother and guardian of an adult son, Mark, age 45, who is diagnosed with Down Syndrome and autism. His speech is limited to simple utterances to express basic wants and needs if prompted but he is incapable of conversation. He is unaware of danger in public places. He is not able to access public transportation and is totally dependent on caregivers who take him to public places and community events. While living with us at home for 42 years, Mark had never been invited to hang out with his peers or to a movie, game of bingo or birthday party in the neighborhood. He has never known integration in the sense of social connections or interaction in the “community.” This situation has changed dramatically for Mark who is now a member of an assisted living community known as Bishop Grady Villas where he lives on an eleven acre campus, rides his adult tricycle independently, visits his friends in neighboring houses (six in all), has his own private room, his own key, enjoys meals in the dining hall or in his own house equipped with its own kitchen, participates in activities on campus, or visits the local pool, gym and other recreational and educational places or shopping areas, accompanied by his Companion.

As a member of the Family Care Council Area 7 of the Agency for Persons with Disabilities and president of Parents Planning Programs (PPP) for the Developmentally Disabled of Florida, Inc., I was actively involved in advocacy and legislation with the Florida Developmental Disability Council (FDDC) on a political level in 2009 and 2010 and as a participant in the FDDC Work Group over a period of five sessions in 2009.

The FDDC has fought PPP's goal of expanding residential options for persons with developmental disabilities as alternatives to either state owned and administered facilities, (disparagingly referred to as "institutions"), or to group homes which are separated from each other by a distancing requirement of 1000 feet -- the Thousand Foot Rule. FDDC has engaged in active lobbying from the beginning of our legislative efforts to amend Florida Statute 419.001 (HB 371 in 2009 & SB 1166 in 2010). Despite their efforts to change the intent of the bill, SB 1166 was passed on June 3, 2010, allowing for exemption of group homes from the Thousand Foot Rule, if part of a planned residential community designed with special amenities, and providing safety, social connections and access to the broader community.

Our complaint against the FDDC concerns the prohibition of certain activities generally considered to be lobbying rather than educating and informing, which are applicable to all ADD grantees, ADD PI-01-1:

Using a nonpartisan approach, grantees would be free to advocate a particular position or viewpoint so long as there is sufficiently full and fair exposition of the pertinent facts to enable the policy maker to form an independent opinion or conclusion. In such an analysis, a grantee would refrain from presenting unsupported opinions, distorted facts, inflammatory and disparaging terms, or conclusions based more on strong emotional feelings than on objective factual conclusions. . . . grantees would have to demonstrate an unbiased attitude when considering alternatives for meeting the needs of [individuals with developmental disabilities]. [Http://www.acf.hhs.gov/programs/add/instructions/PI011.html](http://www.acf.hhs.gov/programs/add/instructions/PI011.html)

Background

The FDDC in 2009 under the direction of Debra Dowds in conjunction with the Advocacy Center which sent out a red ALERT re HB 371, warned that congregate residential communities would be a return to "institutions" and that Home and community-Based Waiver dollars would be "used" for congregate residential communities. The ALERT posted the "unfriendly" and unnecessary amendments filed by Rep. Maria Sachs after HB 371 had passed unanimously on the Florida Senate floor and passed overwhelmingly on all the committee hearings in the House. (See ALERT Attachment A below.)

We received many copies of this ALERT from families who were dismayed by its erroneous and misleading statements. We do not understand how the FDDC, which receives federal funding can abuse its position by attempting to influence legislation in a way that is directly in conflict with the wishes and needs of Floridians with developmental disabilities, and with its own stated mission to advance their rights of freedom and self-determination.

Vigorous lobbying was conducted by the FDDC by their spokesperson, Margaret Hooper, who visited individual legislators, and succeeded in capturing the entire Democratic party's vote, with the exception of Ari Porth, to veto Senate Bill 1166 in 2010.

In addition, an "Action Alert" in 2010 was sent out by Mike Capps, employed by FDDC as Employment Manager and president of APSE. He circulated a similar inflammatory "message" using material put out by Kingsly Ross, a paid lobbyist of Sunrise Corporation. The message claimed that SB1166:

"opens the doors to state funded institutions under the name of 'Choice' ... a bill which authorizes facilities which have virtually no constraints, . . . effectively allows them to become institutions regardless of what they are called, [that] the bill can take community

service dollars away from people served in a traditional group and foster home(s) . . . and underscores the danger inherent in creating institutions. . . Ask [legislators] to vote against SB 1166 because it promotes the development of institutions and discriminates against people with developmental disabilities." (See Attachment B below)

On May 26, 2009 PPP filed a complaint re the red ALERT to Henry Claypool, Director of the Office of Disability of the U.S. Dept. of Health and Human Services. FDDC subsequently scheduled a Work Group, allegedly intended to study residential alternatives in order to reach consensus on legislative language in 2010. However, Ms. Dowds posted their policies to the Center for Medicare and Medicaid Services (CMS) on August 19, 2009, even before the second session of the Work Group convened on August 25th, and long before the Work Group was completed, at a cost of \$40,000. Our request for placement on the agenda to review the submitted document was ignored.

In a letter to Ms. Dowds on Sept. 30, 2009 we stated, "the FDDC's comments to CMS were in direct conflict with the Work Group's promise of fair and unbiased representation of both sides of the issue. It now appears that the Council's position was a *fait accompli*, while adopting the appearance of fairness, even before the Work Group had completed three more scheduled meetings."

The most startling fact is that none of the members of the FDDC had ever visited a planned or intentional residential community and had no agenda to invite representatives of Camphill, L'Arche, Lamb's Farm or Bishop Grady Villas until we raised an objection.

While the Work Group never reached its stated objective, the FDDC continued to set rules and policies. On May 27, 2009 Susan Gold, FDDC Chair, sent out a "message" on Planned Residential Communities legislation warning and alleging use of Med Waiver funds to

- rebuild segregated institutions
- lose control, choice of activities, inclusion, productivity, participation in the full community

Additionally, Debra Dowds, posted a position statement regarding Intentional or Planned Communities to stipulate what they may not or must include (e-mail Jan. 12, 2010; Capitol Update March 3, 2010 Volume 10, Issue 1):

- Provide for housing options only – no workshops, day training, or common dining provided on site.
- Include residents who are both individuals with disabilities (i.e., developmental disabilities and other disabilities) and individuals without disabilities in a *sufficient mix* so as not to create a segregated community.

By this time, the supporters of the legislation to expand innovative residential alternatives had had enough. In a quarterly meeting of the FDDC on March 11, 2010 in Orlando, over fifty families showed up to protest these rules intended to define lifestyle and set quotas. The council was asked to rescind their position, but they refused.

We wish to note that the FDDC provides grants for the Florida Center for Inclusive Communities (FCIC). On March 26, 2009, Nila Benito, Executive Director, sent out a petition to the Florida Coalition for the Education of Individuals with Developmental Disabilities (CEIDD) regarding SB 1166 stating: **"STOP DISCRIMINATION, ABUSE & SEGREGATION OF PEOPLE WITH DISABILITIES!"** (Attachment C below)

Sharon Lewis, Director of ADD, eventually sent a letter to Ms. Benito on the following September 10, 2010, after our continued complaints, in which she stated:

ADD found that you posted two messages to the Florida Coalition for the Education of Individuals with Developmental Disabilities (CEIDD) electronic bulletin board using your UCEDD-affiliated/USF email address. The first post, "Petition Against DD Residential Villages Proposed in FL Legislature" is titled, "*STOP DISCRIMINATION, ABUSE & SEGREGATION OF PEOPLE WITH DISABILITIES". This message appears to utilize the type of "inflammatory and disparaging terms" that are prohibited by ACF policy (ADD-PI-01-1).

ADD would like to remind you that posting advocacy-oriented materials on the CEIDD message board from your UCEDD-affiliated/USF email address affiliates these messages with a federally-funded grant in a questionable manner, particularly when the message could be viewed as inflammatory more so than permissible "non partisan analysis, study and research." We would also like to remind you that under the Developmental Disabilities Assistance and Bill of Rights of 2000, ADD grantees are authorized to educate, advise, and inform Federal, State and local policymakers on issues that have an impact on the lives of individuals with developmental disabilities by emphasizing nonpartisan analysis, study and research.

In a final attempt to set the tone of inquiry, FDDC set up a Focus Group on April 6, 2010, to address specific questions with a facilitator, while ignoring our many questions and protests to the use of unsupported opinions, misrepresentation of the facts, use of inflammatory language, disregard of family wishes in favor of FDDC policies: Please visit our web site at <http://www.pppflorida.org>: [2010 April 6 -- FDDC Focus Group: Facts or Opinions?](http://www.pppflorida.org)

Clarification and Summary

Our family members want and deserve the same equal opportunity as other citizens, now denied them in the proposed rulemaking CMS 2249-P2, to live in a community designed for their safety, services, supports and socially shared interests. As eloquently stated by Sen. Thad Altman, sponsor of SB 1166:

I want to thank all who have worked hard on the Bill for Planned Residential Communities (SB 1166). This is an opportunity for parents to have a choice to put their children in an environment that's best suited for them. We live in a country that's all about freedom and choice, and when you have freedom, choice, competition, the cream rises to the top and this is all about those American values --- by providing an opportunity for those people with developmental disabilities to work and live in a way that they choose to work and live.

FDDC's comments contradict every principle of **freedom, choice and self-determination.**

Contrary to their claims:

1. Med Waiver funding would not be "used" except to reimburse group homes for the usual Residential Habilitation, where funding follows the person.
2. Planned residential communities are not government funded and administered "institutions" like Sunland of Marianna. They are privately developed, uniquely individual and innovative initiatives, subject to local zoning and approval as Planned Unit Developments. "The purpose of a

planned unit development is to encourage the development of planned residential neighborhoods and communities that provide a full range of residence types . . ." F.S. par 163.3202 (3).

3. While providing a safe environment, services, supports and social connection, they encourage a variety of residential options, independent and supported employment, recreation, and interaction with the general community.

However, under FDDC's banner of Integration (defined by location) in the "Community," the FDDC continues to support a more insidious form of segregation via the Thousand Foot Rule contained in F.S. 419.001.

We see FDDC policy as discriminatory and a violation of civil rights by imposing a prohibition against planned communities for our people with developmental disabilities, labeling them as "segregated institutions," while they are freely enjoyed by all other citizens living in a gated, deed restricted, golf, intentional, religious, veterans, etc. community.

We question the legality of FDDC's use of federal funding to promote their own agenda at the expense of the people they are obliged to serve.

We do not believe that the FDDC has the right to determine what is best for individuals with developmental disabilities -- to dictate rules of lifestyle such as dining preferences, opportunities for learning, to impose quotas or to require its stamp of approval on residential *design*. **Choice** of individuals and their families should be the ultimate determiner.

We urgently request that you take action to review their eligibility for funding under a Federal grant in view of their biased agenda and their misrepresentation to block a choice-based and consumer driven initiative for people with developmental disabilities.

Respectfully,

Lila Klausman, Pres.
Parents Planning Programs (PPP), Inc.
Mark's mom
356 Las Olas Dr.
Melbourne Beach, FL 32951
(321) 724-8899 / (321) 432-6045 (cell)
www.pppflorida.org

Cc: Henry Claypool
Sharon Lewis
Sen. Thad Altman
Sen. Bill Nelson
Rep. Bill Posey
Sen. Marco Rubio
Gov. Rick Scott

PLEASE SEE ATTACHMENTS A, B AND C BELOW:

(Continued)

ATTACHMENT A

ALERT

Please Vote No on HB 371- Planned Residential Communities for individuals with Developmental Disabilities unless the following amendments are adopted:

Amendment 1: 600677 by Rep. Sachs

Create new subsection (3) of section 419.001 to read:
Planned residential communities must by their characteristics be community based and satisfy federal guidelines and state rules regarding the characteristics that distinguish community based settings from institutional settings.

Amendment 2: 530169 by Rep. Sachs Create new subsection (3) to 393.501 Rulemaking (3) Such rules shall also address planned residential communities and define, consistent with federal guidelines, the characteristics a planned residential community must have to be considered community-based as distinguished from institutional.

Contact your legislator and as many others as you can in the Florida House of Representatives (you can find them by going to our website(www.fddc.org)) and ask them to **vote YES on Representative Sachs amendments for HB 371(600677 and 530169) and NO on HB 371 if the amendments fail.**

Hurry because HB 371 could be heard as early as this afternoon on the House Floor!

·HB 371 would allow the Developmental Disabilities Home and Community Based Waiver dollars to be used for congregate residential communities that serve, with minimal exceptions, exclusively individuals with developmental disabilities and, as such, segregates individuals with developmental disabilities from the full community and individuals without developmental disabilities.

·According to HB 371, the planned residential communities that could receive Developmental Disabilities Home and Community Based Waiver funding as a result of this legislation, could be developed with the many of the same attributes as an institutional campus such as Sunland Marianna: gated, serving exclusively individuals with developmental disabilities, staff living on site with reduced rent as part of compensation, employment provided on site, day programs provided on site, congregate eating on site, and work days required of residents.

·HB 371 would mark a sweeping and far-reaching change to public policies toward people with developmental disabilities in Florida. Many individuals, families and advocates believe that enacting this proposal, particularly using funding that was intended for an alternative to institutional funding would be a move backward toward segregation, rather than progress forward toward integration.



ADVANCING EMPLOYMENT.
CONNECTING PEOPLE.

[Visit APSE](#) | [Send this Alert](#)

Message from [Florida APSE](#)

Below is information relating to the "DD Villages Bill". Please take action on this NOW. I have attached a link to each of the Committee Members. If for some reason the links do not work go to www.flsenate.gov and follow the links The Committee on Children, Families and Elder Affairs

Please act now!

Mike Capps, President

Florida APSE

Action Alert 5 – SB 1166

By Kingsley Ross

SB 1166 is scheduled to be heard in the Senate Children, Families and Elders Affairs Committee tomorrow morning, Friday March 26. As currently worded, the bill (and its companion HB 645) opens the door to private state funded institutions under the name of "Choice" by changing the siting requirements for group homes. HB 645 was heard this morning and passed its first committee of reference.

Background:

- The bill authorizes facilities, called planned residential communities, which have virtually no constraints placed on them in terms of what services they will provide onsite or how many people will live or be served there. This effectively allows them to become institutions regardless of what they are called.
- The bill can take community service dollars away from people served in a traditional group and foster homes because supporters want to get operating funds from the same budget item.
- An amendment supported by cities is being offered by the sponsor that would set a NIMBY (not in my back yard) precedent by not allowing these facilities in any area of less than 10 acres. This essentially bans these "communities" from urban areas. In effect, the amendment "red lines" these "communities into more rural areas of Florida and underscores the danger inherent in creating institutions.

Action Needed:

Please call or email members of the Senate Children, Families and Elders Affairs Committee. Ask them to vote against SB 1166 because it promotes the development of institutions and discriminates against people with developmental disabilities. It is extremely important that the legislature hear that not all advocates approve of this bill.

- Chair: [Senator Ronda Storms \(R\)](#)
- Vice Chair: [Senator Nan H. Rich \(D\)](#)

- [Senator Nancy C. Detert \(R\)](#)
- [Senator Alex Diaz de la Portilla \(R\)](#)
- [Senator Rudy Garcia \(R\)](#)
- [Senator Anthony C. "Tony" Hill, Sr. \(D\)](#)
- [Senator Charlie Justice \(D\)](#)
- [Senator Stephen R. Wise \(R\)](#)

Michael Capps, Chapter President
[Florida APSE](#)
mikec@fdcd.org

ATTACHMENT C

From: FL-Ed-Advocacy@yahoogroups.com

Sent: Friday, March 27, 2009 4:51 AM

To: FL-Ed-Advocacy@yahoogroups.com

Subject: [CEIDD] Digest Number 955

Florida CEIDD

Messages In This Digest (3 Messages)

1. [Petition Against DD Residential Villages Proposed in FL Legislature](#)€

Posted by: "Benito, Nila" benito@fmhi.usf.edu Thu Mar 26, 2009 7:40 pm (PDT)

STOP DISCRIMINATION, ABUSE & SEGREGATION OF PEOPLE WITH DISABILITIES!

Please sign this petition and forward it to others.

<http://www.ipetitions.com/petition/VetoSB1124/index.html>

[Back to top](#)

[Reply to sender](#) | [Reply to group](#) | [Reply via web post](#)

[Messages in this topic](#) (1)